Ethical Dilemmas in Assisted Reproductive Technologies

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DE GRUYTER

From a strictly biological point of view, the child born through ROPA is not the result of sexual reproduction, which implies that the parents exchange genes to form the embryo through the union of both gametes – male and female. The embryo (the child) receives genes from both parents. With ROPA, the parents continue to be the donor who provides spermatozoa and the woman who provided the egg. But with ROPA, there is a human undertone of participation or collaboration in achieving motherhood. Each woman provides one of the two basic, yet insufficient, pillars to have a child – the eggs and the gestation. The third essential element is the donor, who provides the spermatozoon but does not otherwise participate in the formation of the lesbian couple's family with their children. Denying DI, IVF, or ROPA to a lesbian woman because of her civil status or because of her sexuality is discriminatory and constitutes a breach of all people's right to reproduce. It goes against the principle of autonomy, which is no more than a principle of individual freedom.

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22 ART practice and tourism

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22.1 Introduction

What motivates the global movements of infertile people searching for assisted reproductive technologies (ARTs)? This chapter attempts to answer this question by exploring infertile patients' practices of so-called reproductive tourism (also known as fertility tourism, procreative tourism, and cross-border reproductive care [CBRC]). Reproductive tourism has been defined as "the traveling by candidate service recipients from one institution, jurisdiction, or country where treatment is not available to another institution, jurisdiction, or country where they can obtain the kind of medically assisted reproduction they desire. As such, it is part of the more general 'medical tourism'" (Pennings 2002, 337).

Little is known about the motivations of reproductive tourists in any part of the world. A front-page story in The New York Times (2005) titled "Fertility Tourists Go Great Lengths to Conceive" claimed that infertile Americans were seeking services abroad "in places like South Africa, Israel, Italy, Germany, and Canada, where the costs can be much lower" (Lee 2005, A1). However, economic factors may not be the sole consideration. Eight discrete but often interrelated factors promoting reproductive tourism have been cited repeatedly in the existing literature: (1) Individual countries may prohibit a specific service for religious, ethical, or legal reasons; (2) a specific service may be unavailable because of lack of expertise and equipment; (3) a specific service may be unavailable because of affordability and supply, especially donor gametes and surrogates, leading to shortages and waiting lists; (4) a service may be unavailable because it is not considered sufficiently safe or its risks are unknown, so that countries exercising safety precautions may prohibit procedures that are available elsewhere; (5) certain categories of individuals may be denied a service, especially at public expense, on the basis of age, marital status, or sexual orientation; (6); individuals may fear lack of medical privacy and confidentiality, and thus seek services elsewhere; (7) individuals may fear poorquality medical care and low ART success rates and thus seek services elsewhere; and (8) services may simply be cheaper in other countries (Blyth and Farrand 2005; Deech 2003; Pennings 2002, 2004; Pennings et al. 2008).

These causes of reproductive tourism are still speculative, as relatively little empirical research with reproductive tourists themselves has yet to be undertaken. The now-burgeoning literature on reproductive tourism focuses primarily on legal, ethical, and social justice issues, including concerns over reproductive rights, freedom, and autonomy; legal regulation and harmonization; and global health care equity, including lack of access to ART in resource-poor nations (Blyth and Farrand 2005; Cohen 2006; Collins and Cook 2010; Ikemoto 2009; Jones and Keith 2006; Merlet 2009; Pennings 2008; Smith et al. 2009; Stephenson 2009; Storrow 2005a, 2005b). Those scholars who have explored infertile patients' perspectives have relied primarily on anonymous, self-administered research tools, such as survey questionnaires distributed through clinics, the Internet, or patient-support groups (Blyth 2010; Nygren et al. 2010; Shenfield et al. 2010; Thorn and Dill 2009). Few studies have

employed person-centered, qualitative (ethnographic) interviewing methods with infertile patients participating in CBRC.

Furthermore, most of the existing literature on reproductive tourism focuses on the Western nations and Australia, with particular attention given to issues of patient border crossing between European Union nations (Blyth 2010; Deech 2003; McKelvey et al. 2009; Pennings 2004; Pennings et al. 2008; Shenfield et al. 2010). To date, only one study has focused on Latin America (Smith et al. 2009), and several scholars have expressed concern about reproductive "outsourcing" to India, especially regarding gestational surrogacy (Jones and Keith 2006; Smerdon 2008/9; Stephenson 2009). That reproductive tourism is a truly global phenomenon has been recognized by the European Society for Human Reproduction and Embryology's Task Force on Ethics and Law (Pennings et al. 2008); the International Committee for Monitoring Assisted Reproductive Technology (Nygren et al. 2010); the International Forum on Cross-Border Reproductive Care (Collins and Cook 2010); the Society of Cross-Border Reproductive Care (SCRC), which held its first board meeting in Vienna, March 26-27, 2010; and the International Federation of Social Workers, which has drafted a policy paper on cross-border reproductive services (Blyth and Auffrey 2008).

Given this growing concern about the global practice of ART tourism, very little is known about the forces that motivate infertile persons to undertake international travel in their quests for conception (Inhorn 1994). Only through in-depth analysis of the actual stories, desires, travel trajectories, and experiences of reproductive tourists themselves may we begin to shed light on the complex calculus of factors governing this global movement of reproductive actors.

22.2 Background and methods

This chapter examines ART practice and tourism from the perspective of men and women who have crossed international borders in search of solutions to infertility. It is based on a three-year study (2007-2009) of reproductive tourists to the Middle East and the United States. The study was carried out in ART clinics in two distinct locales: Dubai, United Arab Emirates (UAE), and Yale University, in New Haven, Connecticut. Nearly 300 reproductive tourists, as well as traveling egg donors and surrogates, embryo couriers, and ART clinic staff, were interviewed. Reproductive tourists hailed from more than 50 nations and 6 continents (Africa, Asia, Australia, Europe, North America, and South America). Interviews lasted from half an hour to three hours, depending on the circumstances of the research subjects. The majority were conducted in private rooms in ART clinic settings, although some interviews were conducted over the telephone or in patients' homes. All interviews were conducted with written informed consent, and the research was approved by Yale University's Human Subjects Committee, IRB Protocol # 0809004256. The interviews were ethnographic, involving an interview guide with many open-ended questions. All interviews were administered to research subjects by one of the authors, a medical anthropologist with long-term research experience on infertility and ART in both the Middle East and United States (1985-present). Interviews were conducted in either English or Arabic, depending on research subjects' preferences. In addition, the authors undertook extensive research on the various legal and

religious precedents affecting ART practice in these settings (Inhorn and Patrizio 2009; Inhorn, Patrizio, and Serour 2010).

In summary, to our knowledge, this study represents the first long-term, comparative, qualitative investigation of reproductive tourism from the point of view of patients themselves. It attempts to answer the question posed at the outset of this chapter - namely, what motivates the global movements of infertile people searching for ART?

22.3 Major findings

Three overarching findings need to be highlighted at the outset:

First, the language referring to "reproductive tourism" and the like, which has been promoted by the Western media and taken up by the ART research community, is highly problematic. Most reproductive travelers in our study vociferously critique the term tourism. Their own travel, they explain, is undertaken out of the desperate need for a child and is highly stressful and costly. Because "reproductive tourism" implies fun, leisure, and holidays under the sun, it is considered a cavalier and insensitive term. As one Australian patient put it, "'reproductive tourism' sounds like a gimmick," which makes a mockery of infertile people's suffering. In virtually every case, infertile couples describe their preferences not to travel if only legal, trustworthy, and economical services were made available closer to home.

Reproductive travelers' own critique of the term "reproductive tourism" suggests the need for some scholarly revision. To that end, the term "reproductive travel" will be used henceforth in this chapter. To perpetuate the concept of "reproductive tourism" may be to misrepresent the subjective world of reproductive travelers, very few of whom experience their travel in truly touristic terms. Instead, the notion of reproductive exile may be closer to most patients' subjective experience of reproductive travel (Inhorn and Patrizio 2009; Pennings 2005). The term exile has two meanings: either forced removal from one's native country or a voluntary absence. Both meanings are accurate to describe reproductive travel. Namely, in our qualitative study, reproductive travelers describe how they feel forced to leave their home countries in order to access safe, effective, affordable, and legal infertility care. Their choice to use ART to produce a child is voluntary, but their travel abroad is not.

Legal barriers in particular bespeak the politics of exile, and such politically motivated reproductive exile may be increasing. For example, in recent years, several Western European nations, including Germany, Norway, and the United Kingdom, have enacted strict legislation prohibiting some or all forms of gamete donation, especially anonymous gamete donation, as well as gestational surrogacy (Jones and Cohen 2007; Pennings 2004; 2008; Pennings et al. 2008; Shenfield et al. 2010). In Southern Europe, Spain prohibits surrogacy, Italy prohibits both surrogacy and gamete donation, and France prohibits lesbian and single women from accessing ART (Inhorn, Patrizio, and Serour 2010; Matorras 2005). Such restrictions have triggered European reproductive travel on a massive scale, especially to the "white" post-Soviet bloc of Eastern Europe (e.g., countries such as the Czech Republic, Romania, and Russia). There, clinics can "employ the Internet to attract fertility tourists with promises of cut-rate in vitro fertilization, high success rates, liberal reproductive policies, and little administrative oversight" (Storrow 2005a, 307).

Furthermore, young women in these countries may comprise a vulnerable population of egg donors, who are compelled out of economic necessity to sell their ova in the local reproductive marketplace. Given the newly recognized category of the traveling foreign egg donor who seeks economic mobility through the sale of her body parts (Heng 2007), unregulated fertility travel has been compared to sex tourism, as young women in the economically deteriorated postsocialist societies discover that prostitution and egg donation offer economic rewards. As Storrow (2005a, 327) argues, "egg donation, like prostitution, will be especially attractive in regions of the world where large numbers of women with few choices want to improve their economic circumstances by any means available."

Our second major finding is that most reproductive travelers lament the lack of necessary ART services in their own residential locales, and wish that they could remain at home for a variety of reasons. First, home represents a comfort zone for most infertile patients. They are familiar with the medical system, may have developed emotional attachments to particular clinics and obstetrician-gynecologists, and speak the same language and share cultural assumptions with the medical staff in the home country. Furthermore, patients may have well-developed social-support networks at home, including family members and friends who can be counted on to demonstrate tender, loving care during the lengthy and sometimes physically challenging ART treatment process.

In addition, infertile patients consider the pragmatics of reproductive travel – including absorbing economic costs, making travel arrangements, finding appropriate lodging, acquiring travel visas, transporting cold-chain-sensitive medications, communicating with foreign clinics, and being away for extended periods – to be arduous. Patients often complain that reproductive travel is emotionally exhausting, financially draining, and logistically impractical, and should be avoided at all costs, if possible.

For many infertile patients, taking time off from work is a major problem. Men and women who work must schedule ART cycles within the parameters of their busy lives. Traveling often involves asking for permission from employers to use vacation time, medical-disability leave, or unpaid leave. Furthermore, many ART-seeking couples have major careers, which may be disrupted by reproductive travel. In our study, men often made noble attempts to fit travel within the demands of their professions. Sadly, however, many career women had left their professions altogether, due to the impossible demands of balancing work with reproductive travel for ART. Women were sometimes forced to travel alone, because their husbands were unable to escape demanding jobs. Indeed, reproductive travel is seen as jeopardizing work, because it requires time off, depletion of vacation and sick days, or unpaid leave. Permission must be sought, thereby revealing infertility problems to employers. With the global economic downturn, jobs are less secure than before, making time off seem especially threatening. Furthermore, many ART patients are devoted couples who want to stay together, literally and figuratively, during the entire ART treatment process. Reproductive travel may pull them apart.

Finally, infertile patients have legitimate concerns about the health risks of travel during the ART treatment process. In our study, several travelers, particularly those coming from South Asia and Cyprus, had encountered serious, even life-threatening, reproductive emergencies during periods of travel, including ovarian hyperstimula-

tion syndrome, ectopic pregnancies, and the development of severe reproductive-tract infections.

Our third major finding involves the "why" question – namely, there are many additional causes of reproductive travel above and beyond those cited in the existing literature. Listening to reproductive-travel stories through fine-grained ethnographic research is key to understanding what propels infertile couples on their transnational quests for conception. In the next half of this chapter, we highlight the various causes of reproductive travel to and from the UAE, as well as to an Ivy League ART center on the East Coast of the United States.

22.3.1 The United Arab Emirates

The UAE proved to be a fascinating global hub in which to study the phenomenon of reproductive travel. ART centers in the UAE are cosmopolitan, with infertile patients representing many nations. In this study, in-depth, ethnographic interviews were conducted with nearly 220 individuals, representing 125 patient couples hailing from exactly 50 countries. The majority were Indian, followed in rank order by Lebanese, Emiratis, British, Pakistanis, Sudanese, Filipinos, and Palestinians. Both male and female infertility were implicated, but male infertility was seen as a particularly emasculating cause of secret travel. Women experiencing female infertility, especially those from Africa, the Middle East, and South Asia, were often under incredible social and marital pressure. In these cases, supportive husbands were often "escaping" with their wives to the UAE in order to seek solutions to the childlessness.

In this study, three major patterns of reproductive travel were identified: (1) reproductive travel to the UAE, (2) reproductive travel from the UAE, and (3) reproductive travel to and from the UAE. Factors that are not generally highlighted in the scholarly literature on reproductive travel are included below.

22.3.1.1 Reproductive travel to the UAE

In this study, participants described six major reasons they had come to the UAE in search of ARTs, as follows:

- 1. The emirate of Dubai is luring travelers as a high-tech, highly educated global city. Reproductive travelers are attracted to Dubai in part because of its recent marketing as a high-tech medical-care setting (e.g., Dubai Health Care City).
- 2. In addition, the UAE makes it easy for most reproductive travelers to enter on a multimonth visitor's visa, which allows them to complete an entire ART cycle (minimally 4–6 weeks) with only one trip to the country.
- 3. In some parts of the Middle East (e.g., Oman, Yemen) and Sub-Saharan Africa (e.g., Djibouti, Sudan), ART clinics are either completely absent or minimally present, and the UAE represents the closest and easiest country in terms of access.
- 4. Many reproductive travelers decide on the UAE through word-of-mouth referrals a) from regional networks of physicians and from b) patient Web sites and chat rooms where patients can share their preferences.

22.3 Major findings

- 5. In Europe, though ARTs are readily available, many countries have enacted multiple restrictions, including age limits and strict embryo-transfer guidelines. Thus, Europeans are coming to the UAE to bypass these restrictions.
- 6. Many reproductive travelers from the United Kingdom are seeking refuge in the UAE after spending years on National Health Service waiting lists. Although publicly funded ART is available in the United Kingdom, they operate on a lottery system and are often deemed by patients to be low quality and ineffective.

22.3.1.2 Reproductive travel from the UAE

Just as infertile couples are traveling to the UAE for ART services, many of them are also flowing out of the country for a variety of reasons. Patients in this study provided nine reasons they, or others they knew, had left the country at some point in time to seek ART services elsewhere. Again, some of the factors reported are rarely highlighted in the reproductive-travel literature.

- 1. Some reproductive travelers leave the country (or travel to a different emirate) in search of privacy/secrecy in a milieu where both infertility and ART are still highly stigmatizing, especially among the local Emirati population.
- 2. Reproductive travelers who have attempted to access lower-cost services in government clinics in the UAE have faced long delays and waiting lists, prompting them to leave the country (or the emirate). This is especially true of immigrant workers, who have lower priority and lower rates of subsidization than the local Emirati population.
- 3. The UAE is one of the few Middle Eastern countries to enact ART legislation. As with other Sunni-majority Middle Eastern countries, the UAE does not permit any form of third-party reproductive assistance (i.e., sperm and egg donation, embryo donation, or surrogacy) (Meirow and Schenker 1996; Serour 2008). Reproductive travelers who require third-party reproductive assistance to overcome their infertility must travel outside the Sunni Muslim countries. The UAE also prohibits fetal reduction (a form of selective abortion when too many embryos implant in the uterus) and cryopreservation of embryos. According to a new law enacted in January 2010, all of these services are legally banned under Islamic sharia law in the UAE, including for non-Muslim immigrants.
- 4. Reproductive travelers are often keenly aware of the comparative costs of ART in different countries and may travel to a cheaper locale; this is especially true of immigrants who may be able to access state-subsidized services based on ongoing citizenship rights in their own countries. (The UAE does not grant citizenship to non-Emiratis.)
- 5. More affluent residents of the UAE are often actively engaged in Internet searches for ART clinics abroad and are attracted by fertility "tourist packages" offered in countries such as India, Singapore, and Thailand. They may regard these locales not as holiday sites, but rather as trustworthy countries in which to obtain the services they need.

- 6. Immigrants in the UAE also display "medical (ex)patriotism" namely, a belief that their home country offers higher-quality medical services than their host country. This patriotic attachment to home propels many infertile couples back to their natal countries during month-long annual leaves.
- 7. These travels back home are often justified by reproductive travelers who have faced poor-quality medical care in the UAE. Some travelers recite medical horror stories in which they or a loved one experienced serious complications and near-death experiences at the hands of local medical personnel.
- 8. In addition, expatriates often prefer to try ART back home because they will be hosted and cared for by their families. Some couples consider this kind of family support, especially by parents, critical.
- 9. Finally, some reproductive travelers are leaving the UAE in the third trimester of their ART pregnancies in order to deliver their offspring in the West (e.g., Canada, the United Kingdom, or the United States). The desire is to produce an "anchor baby" who will eventually confer citizenship rights to the whole family.

22.3.1.3 Reproductive travel to and from the UAE

In the study, many infertile patients had traveled "to and from," or in and out of the UAE, for a variety of reasons. Three major factors for these back-and forth movements, which are rarely addressed in the existing literature, are highlighted:

- 1. Reproductive travelers end up receiving fragmented care because of their difficulty in accessing the full range of services in the UAE. For example, those needing donor eggs may travel to Cyprus or Lebanon. Those needing fetal reduction (abortion) may travel to India or the United Kingdom. And those with financial constraints may undertake diagnostic laparoscopy in India to save on costs.
- 2. Infertile couples who have frozen embryos in storage abroad may end up having to retrieve them transnationally, either by traveling abroad or hiring the services of an embryo courier. As of 2010, both cryopreservation and embryo couriers have been outlawed in the UAE, meaning that more couples will be forced to travel outside the UAE for embryo-cryopreservation services.
- 3. Infertile couples who are not successful after repeated trials of ART end up doctor shopping across the emirates, regionally, or, in some cases, globally, effectively moving back and forth across the Middle East.

22.3.2 The East Coast of the United States

Whereas the UAE represents a global hub for both labor migration and reproductive travel, the coastal cities of the United States have tended to draw European, East Asian, and Latin American reproductive travelers seeking specific ART services. In our study, conducted at Yale University's Fertility Center, reproductive travelers represented nine nationalities (American, Argentinean, Australian, British, Canadian, Egyptian, German, Italian, and Korean), and five self-identified ethnicities (Afro-Caribbean, Arab, Asian, Caucasian, and Jewish – including a daughter of Holocaust survivors). In most cases, these infertile patients had traveled to the Yale Fertility Center because of religious and legal restrictions

faced in their home countries (especially limitations on gamete donation and surrogacy). However, there were other reasons for travel to Yale, as follows:

- 1. Yale is seen as running a prestigious, university-based ART program with Ivy League donors (both sperm and egg). For couples needing donor services, they are hopeful that they will receive the gametes of highly intelligent Yale students. even though the clinic makes no such promises. (In fact, most donors come from neighboring communities and colleges.) Beyond the lure of superior, Ivy League gametes, some couples simply have greater trust in university-based clinics than in the private practice world of ART.
- 2. The Yale IVF physicians, all foreign born, are part of the highly diverse and global reproductive-medicine community. The physicians themselves are a major attraction for reproductive travelers: They are Western trained, yet speak other languages, as advertised on the clinic's Web site. Thus, patients from those countries feel a cultural and linguistic affinity that is compelling, especially when arcane medical information must be communicated between parties.
- 3. Reproductive travelers from other countries are generally fleeing religiously based legal restrictions in their home countries. This is especially true for the many Italian couples coming to the clinic. In Italy, a 2004 law prohibits most forms of ART, including gamete donation and surrogacy, making it the second most restrictive country in the world (other than Costa Rica, where ARTs are banned altogether). The United States, on the other hand, is known as the "Wild West" of infertility treatment, since there is no national regulation of ART. Thus, most couples are coming to the United States to escape stricter legislation, especially that which disallows various forms of third-party reproductive assistance. This is particularly true of middle-aged career couples who have delayed childbearing but are unable to access donor oocytes and surrogates in their home countries. The United States is viewed as one of the few trustworthy sites for accessing donor technologies and surrogacy, particularly compared with Spain or India, the two major global hubs for these practices.
- 4. Connecticut is one of the relatively few states that allow commercial surrogacy. Neighboring New York does not, thereby propelling many reproductive travelers to Connecticut (as opposed to New York City). In addition, the surrogates themselves must travel to Connecticut in order to undergo the necessary procedures. Several such traveling surrogates were interviewed in this study, and in all cases, they say they were motivated to become surrogates because of the compassion they felt for close friends and family who had suffered through infertility. These American surrogates considered carrying the babies of foreign-born couples to be a cross-culturally enriching experience.
- 5. Connecticut is also one of the only U.S. mandate states those in which state law mandates economic coverage of IVF-related treatments, including partial coverage of some of the services of third-party gamete donation, for state residents. Thus, unlike the majority of states, Connecticut subsidizes this form of fertility treatment for its citizens, creating equal access for all infertile couples regardless of economic means. Foreign reproductive travelers do not share these privileges of access and subsidization. However, some former residents of Connecticut, including foreigners who have completed medical school or graduate training at Yale, retain their state residence in order to travel back for subsidized reproductive services.

22.4 Conclusion

In the new millennium, scholars, ART professionals, and the global media now recognize that reproductive travel is a growing global phenomenon. As infertile patients pursue ever more diverse treatment options around the globe, policymakers ponder whether limits should be set on the technologies themselves and on the reproductive travel surrounding them (Deech 2003). As one of the main scholars of reproductive travel, Guido Pennings has noted, "The more widespread this phenomenon, the louder the call for international measures to stop these movements" (Pennings 2002, 337). A great deal of speculation - including open condemnation by highly regarded policymakers in internationally esteemed journals - suggests that reproductive travel has created an internationally "lopsided market in baby making," which requires careful ethical and legal regulation on a global level. As Harvard University business professor and policy analyst Debora Spar (2005, 533) argues, "As science continues to expand our menu of reproductive options, it will be increasingly important to engage in some kind of political debate and to ensure that some consideration stretches beyond the desires of individual parents."

This chapter has provided some critical empirical evidence from the perspective of individual prospective parents – a perspective lacking in the growing policy debates. As a multisited ethnographic investigation, this study has uncovered the multiple desires, intentions, and frustrations of infertile couples as they travel to and from ART sites in two disparate parts of the world. As such, the empirical findings of this study should be of great importance to both ART social policy and clinical practice by providing insights into the motivating factors, experiences, and concerns of reproductive travelers themselves as they make their way around the globe in pursuit of conception. Their concerns cannot be known a priori. Instead, it should be the role of scholars to gather important information from reproductive travelers on every continent, thereby shedding light on a world of global reproductive travel that is burgeoning but still shrouded in mystery.

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